

## The Effect of a Family-Based Training Program on the Care Burden of Family Caregivers of Patients Undergoing Hemodialysis

### Abstract

**Background:** The family caregivers of patients undergoing hemodialysis are faced with multiple physical, psychological, social, economic, and spiritual problems that increase their care burden. The present study was conducted to determine the effects of a family-based training program on the care burden of family caregivers of patients undergoing hemodialysis. **Materials and Methods:** The present controlled, randomized, clinical trial was conducted on 70 caregivers of patients undergoing hemodialysis in Ali Asghar and Zahray-e Marzieh hospitals in Isfahan, Iran, in 2017. After conducting convenient sampling, 70 participants were randomly assigned into 2 groups (35 in each group). The experimental group received the family-based training program and the control group received usual care plan. Data were collected using the Zarit Burden Scale before, immediately after, and 1 month after the intervention and were then analyzed by independent *t*-test, Chi-square, and Analysis of Covariance (ANCOVA) repeated measure. **Results:** The results showed that both groups were homogeneous in terms of their demographic data and showed no significant differences. The main effect of group was significant, indicating a significant decrease in care burden in the experimental group after the intervention ( $F_{1,67} = 1089, p < 0.001$ ). However, the interaction of time and group was not significant, indicating insignificant difference in burden 1 month after intervention ( $p > 0.05$ ). **Conclusions:** Since the family-based training program successfully reduced the burden of care immediately after intervention, similar family-based training programs are recommended to be designed and developed. However, insignificant time effect suggests further researches of long time effects of such program.

**Keywords:** Burden, family-based training, family caregivers, hemodialysis, Iran

### Introduction

Chronic diseases are a major contributor to morbidity, mortality, and decreased quality of life and have become a national public health crisis.<sup>[1]</sup> Chronic kidney disease is an increasingly prevalent global problem that causes numerous issues for the patients, their families, the health-care team, and future economies.<sup>[2]</sup> The global prevalence of chronic kidney disease is about 500 million, that is, 1 out of every 10 people suffers from this disease.<sup>[3]</sup> Based on the statistics provided by the Iranian Ministry of Health and Medical Education, there are approximately 39,000 patients with kidney failure in Iran<sup>[4]</sup> and 1200–1600 people are annually added to this figure.<sup>[5]</sup>

End-stage renal patients require medical therapies for survival, including hemodialysis and kidney transplantation. Patients turn to hemodialysis due

to the unavailability of kidneys for transplantation.<sup>[6]</sup> Hemodialysis remains the most common treatment for chronic kidney disease in the United States (over 90% of the patients), Iran, and many other countries.<sup>[7]</sup> In Iran, a total of 25,934 patients were under hemodialysis in 2013.<sup>[8]</sup> Chronic kidney disease and treatments such as hemodialysis alter the patients' lifestyle, health status, and social roles. In the long term, these factors reduce their living standards, cause physical and mental problems, and limit recreational, social, and occupational activities. These patients are therefore in need of care and support.<sup>[9]</sup>

The families of patients are responsible for a major part of the care and support given to these patients and carry a considerable care burden.<sup>[6]</sup> The care burden is the physical, psychological, and social distress that carries about caring for chronic patients<sup>[10]</sup>

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that was divided into objective and subjective groups. The objective burden care refers to the negative effects of disease on the caregivers' objective issues such as the disruption of family relationships; restrictions on social activities, work, and recreation; and physical as well as financial problems. Subjective burden care is emotional reactions of caregivers to the patient and his care, including problems like stress, feeling of loss, and regret.<sup>[6]</sup> Dimensions of burden of care include time-based care burden, evolutionary care burden, physical care burden, social care burden, and emotional care burden.<sup>[10]</sup> Some evidence suggests that the care burden is higher after experiencing problems with adaptation to these conditions.<sup>[11,12]</sup> Research shows that the caregivers of patients undergoing hemodialysis experience an enormous care burden in terms of the responsibility of caregiving and may suffer from physical and psychological problems,<sup>[10,12-15]</sup> such as anxiety, depression, exhaustion,<sup>[10]</sup> hypertension, chronic pain, and gastrointestinal problems.<sup>[16]</sup> It is therefore necessary for health-care workers to be aware of the important role played by the main family members of patients with kidney disease in caregiving and effectively communicate with them and provide support when they require it.<sup>[17]</sup> Because of their constant contact with the patients and their relatives, nurses play a major role in the interactions established with the patients' families and can provide the necessary knowledge, skills, and support for improving the quality of home care. They can play an important role in enhancing the quality of care and reducing the care burden experienced by caregivers of dementia,<sup>[18]</sup> cardiac,<sup>[19]</sup> and psychiatric<sup>[20]</sup> patients through evaluating the family's health-related needs and providing them with accurate and timely training.<sup>[18-20]</sup>

Educational interventions for the caregivers and family members of these patients enhance the quality of home care significantly.<sup>[4]</sup> Family-based training programs are one of the interventions used for promoting the knowledge and attitude regarding the nature of problems and enhancing communication and problem-solving skills.<sup>[18]</sup> Using various training methods helps increase the knowledge of both patients and their families regarding the disease and helps improve their adaptation to the disease, the use of communication and problem-solving skills, anger and stress management, and quality of life.<sup>[21-23]</sup> Some studies have shown the effectiveness of family-based training programs in reducing the care burden experienced by the caregivers of other chronic illnesses such as cancer,<sup>[24]</sup> heart failure,<sup>[19]</sup> dementia,<sup>[18]</sup> and mental disorder.<sup>[20]</sup> Few educational programs have conducted on the burden of caregivers of patients undergoing hemodialysis. For example in a study conducted in Turkey, Mollaoğlu *et al.*<sup>[15]</sup> investigated the effect of educational program on caregiver burden of hemodialysis and reported that these programs were effective in reducing the burden of caregivers. However, this study is conducted without a control group.<sup>[15]</sup> In another study, Khorami-Markani *et al.*<sup>[4]</sup> evaluated the

effect of a family-centered educational program on the home-care knowledge of caregivers of patients undergoing hemodialysis and reported positive results. However, this study is conducted on the knowledge of caregivers. The process of hemodialysis has major effects on the life of the patients and their families. Moreover, the majority of studies have focused on the patients and neglected the mutual interaction between the patients and their families.<sup>[6]</sup> The present study was therefore conducted to examine the effect of a family-based training program in the care burden of family caregivers of patients undergoing hemodialysis.

## Materials and Methods

The present study was a two-group three-stage clinical trial [IRCT20170812035635 N2] examined the effect of a family-based training program on the care burden of family caregivers of patients undergoing hemodialysis in Ali Asghar and Zahray-e Marzieh hospitals in Isfahan, Iran, from June to October 2017. The study population consisted of the family caregivers of patients undergoing hemodialysis. The inclusion criteria were age  $\geq 18$  years, being the main caregiver of the patient and responsible for all their tasks, a willingness to participate in the study, ability to communicate, read and write in Persian, the absence of known mental disorders (based on asking from the caregiver), the absence of physical disorders, and not being a member of any health-care teams. The exclusion criteria consisted of the noncooperation of the caregivers until the end of the study and being absent from the class for two sessions. Sample size was calculated with regard to similar studies;<sup>[25]</sup> the sample size for each group was set at 32 participants;  $Z_1$  was the confidence interval that was considered to be 95%,  $Z_2$  was test's power that was 80%, and  $d$ , which was the least difference between the mean of changes in score of burden of care between both groups, was considered to be 0.70. Ten percent was added to the overall sample size to cover the probability of dropouts and the final sample size reached to 70 subjects.

The sample size was 70 caregivers of patients undergoing hemodialysis and the caregivers were randomly (using a table of random numbers) assigned to an experimental and a control group. Figure 1 presents the CONSORT diagram of the sample allocation. Data were collected using a demographic questionnaire and the Zarit Burden Scale (ZBS)<sup>[26]</sup> before, immediately after, and 1 month after the intervention. The demographic questionnaire for the caregivers inquired about age, gender, marital status, education, occupation, relationship with the patient, duration of caregiving, income, place of residence, type of residence, and living with the patient or not. The ZBS includes 22 items on personal, social, emotional, and economic strains in the 2 subjective and objective groups and was completed by the researcher by interviewing the family caregivers. The items in this questionnaire are scored based on a 5-point Likert scale, from "never" (score 0) to

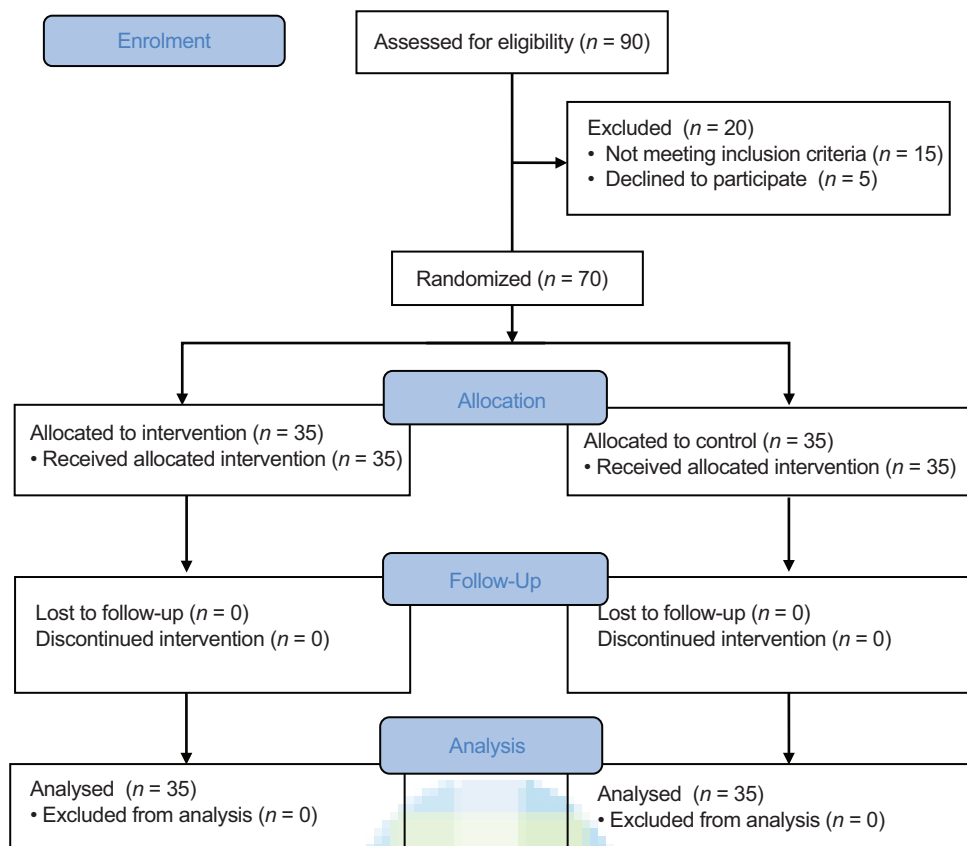


Figure 1: CONSORT Flow diagram for the study

“nearly always” (score 4). The subjects select “never” (0), “rarely” (1), “sometimes” (2), “quite frequently” (3), or “nearly always” (4) for each item. The total score ranges from 0 to 88. The lowest score of care burden (0) indicates no burden, whereas 88 shows maximum burden and 61–88 indicate severe, 30–60 moderate, and below 30 mild care burden.<sup>[27,28]</sup> In 2004, Navidian *et al.*<sup>[27]</sup> translated the ZBS into Persian, measured its qualitative content validity, and reported its test–retest reliability as 0.94. They obtained a Cronbach’s alpha of 0.86 for the sample size of 64, which indicates the acceptable internal reliability of this measure.

After obtaining approval for conducting the study, first researcher visited Ali Asghar and Zahray-e Marzieh hospitals and asked for the permission of their hemodialysis ward head and hospital director after introducing themselves and the research objectives and methods. They then invited the eligible subjects to participate in the study and obtained their written consent. Then, 35 couples (70 participants) were assigned into 2 groups (35 in the experimental and 35 in the control group). The subjects were informed about the study process and their role in the study. Moreover, they were notified and followed to participate in the intervention sessions. Hereby, the attrition rate was 0%. The family-based training program given consisted of eight 90-min sessions of lectures, group discussions, practice, homework, and question and answer based on an educational booklet,<sup>[25]</sup> which were held

twice per week in classrooms located in the hospitals at both centers. At the beginning of each session, previous discussions and participants’ homework were reviewed and the sessions ended with questioning and group discussion. In addition, relaxation techniques were conducted at the beginning and end of each session. The validity of the educational booklet and the demographic information was confirmed by 10 faculty members at the School of Nursing and Midwifery, Isfahan University of Medical Sciences. A summary of the content of each session is provided in Table 1. The control group simply discussed their problems, feelings, and experiences with each other in two sessions supervised by the researcher at a time other than the time of implementing the intervention for the experimental group at agreed times (the afternoon of hemodialysis days). This intervention was carried out to appreciate the patients’ participation in the study. To comply with the ethics of research, the control group received copies of the educational booklet at 1 month after intervention. Data were analyzed in SPSS software (version 18.0, SPSS Inc., Chicago, IL, USA) at the significance level of  $p < 0.05$ . The repeated-measures ANCOVA model assumptions were checked with different tests; the normality of the dependent variables was checked using the Kolmogorov–Smirnov test. The variance homogeneity of variances was checked using Levene’s test and the covariance homogeneity using Box’s  $M$  test.

**Table 1: The objectives and summary of the content of the family-based training sessions**

number of sessions	objectives and summary of the content
Session 1	Introducing the researcher, the objectives, and content of the sessions and the structure and function of the kidneys, completing the ZBS and the demographic form by the caregivers
Session 2	Promoting knowledge and awareness about the end stage of kidney disease (definition, etiology, symptoms, complications, treatment with hemodialysis, complications of treatment, etc.)
Session 3	Maintenance and promotion of physical health and the importance of self-care (adequate rest and sleep, exercise, nutrition, 6- and 12-month visits to the doctor)
Session 4	Promoting the skills of communicating with the patients and modifying family relations, such as by establishing relationships with the patient, effective communicative methods, improving this process in the family, and effective methods of expressing emotions
Session 5	Promoting coping skills by learning about stress management (e.g., muscle relaxation and deep breathing) and problem-solving techniques
Session 6	Promoting family and social relationships, enhancing the social dimension by interacting with support groups and organizations, having healthy recreational and leisure activities, introducing family support resources and the means of accessing support services, for example, Iranian Hemodialysis Association
Session 7	Strengthening the spiritual dimensions, learning about methods of promoting life expectancy (prayer therapy)
Session 8	A review of the discussed points, receiving feedback from the members regarding the discussed points, question and answer, group discussion, and completing the ZBS

### Ethical considerations

This paper is based on an MSc thesis approved by the Ethics Committee of Isfahan University of Medical Sciences (IR.MUI.REC.1395.3.950). The major ethical considerations of this study included obtaining the subjects' informed consent and ensuring their anonymity and their right to withdraw from the study at any time.

### Results

This study was conducted on 70 participants. Participant characteristics are presented in Table 2. The results showed that both groups were homogeneous in terms of demographic characteristics and had no significant differences in this regard. The normality of the dependent variables was supported using the Kolmogorov–Smirnov test ( $p > 0.05$ ) and the homogeneity variances also were confirmed ( $p > 0.05$ ).

The baseline comparison of the care burden between intervention and control groups indicated significant differences. In order to controlling for pretest scores, the

repeated measure ANCOVA was adopted. The results showed that the main effect of group was significant, indicating a significant decrease in care burden in the experimental group after the intervention ( $F_{1,67} = 1089$ ,  $p < 0.001$ ). However, the interaction of time and group was not significant [Table 3].

### Discussion

As the results of the present study showed, most caregivers were female, who were daughters or spouses of the hemodialysis patients; studies of the other countries also showed that women in most cases are the main caregiver of patients in the family. Usually, the caregivers are middle aged, married women.<sup>[10,14,15]</sup> Jadhav *et al.*<sup>[13]</sup> suggest that most of the caregivers of patients with chronic diseases in Asian families are female. According to the study by Mollaoğlu *et al.*<sup>[15]</sup>, female family caregivers are usually more sentimental and sensitive to the caring needs of patients and, compared to men, have greater ability in the management of problems and establishment of an intimate relationship with the patient.

The results of the present study showed the effectiveness of the noted intervention in reducing the care burden of caregivers of patients undergoing hemodialysis. The results obtained immediately after the intervention revealed a significant decrease in the care burden of caregivers in the experimental group ( $p < 0.05$ ). Similarly, other researchers have investigated the effects of supportive training programs, including the family-based training program, on the care burden of caregivers of patients with breast cancer,<sup>[29]</sup> cardiac disease,<sup>[19]</sup> mental illness,<sup>[20]</sup> and Alzheimer's disease<sup>[18]</sup> and children with attention deficit hyperactivity disorder (ADHD).<sup>[30]</sup> All these studies showed that the care burden of caregivers reduced significantly in the experimental group after the intervention ( $p < 0.05$ ). In the present study, 66.9% of the subjects experienced a severe care burden, which is in line with the results of most studies, including studies by Abbasi *et al.*,<sup>[10]</sup> Alnazly,<sup>[12]</sup> Jadhav *et al.*,<sup>[13]</sup> Bayoumi *et al.*,<sup>[14]</sup> and Mollaoğlu *et al.*,<sup>[15]</sup> who showed that caregivers of patients undergoing hemodialysis experience a severe care burden. In contrast to these findings, however, Rioux *et al.*<sup>[16]</sup> reported a low care burden in their subjects. This disparity may be due to the patients' higher self-care abilities and the performance of hemodialysis at night, which did not intervene with the caregivers' activities of daily living. The present findings suggest a significant reduction in care burden immediately after the family-based training program in the experimental group ( $p < 0.05$ ), which is consistent with the results of other studies.<sup>[18,24,29,31]</sup> In contrast, Martín-Carrasco *et al.*<sup>[32]</sup> found no significant differences in the care burden of caregivers of patients with Alzheimer's disease before and immediately after a 4-month psychological training program. This lack of significant results may be due to the duration of the intervention and the nature of the disease.



**Table 2: Comparison of the caregivers' demographic characteristics between experimental and control groups**

Variables	Groups	Experimental	Control	<i>p</i>
Age (years)	Mean (SD)	45.80 (13.90)	45.50 (13.30)	0.196*
	Median (minimum-maximum)	45 (20-70)	48 (25-70)	
Duration of care (months)	Mean (SD)	79.90 (68.40)	65.40 (60.30)	0.323*
	Median (minimum-maximum)	60 (4-288)	48 (4-240)	
		<b><i>n</i> (%)</b>	<b><i>n</i> (%)</b>	
Gender	Female	29 (82.90)	26 (74.30)	0.382**
	Male	6 (17.10)	9 (25.70)	
Marital status	Single	5 (14.30)	7 (20)	0.526**
	Married	30 (85.70)	28 (80)	
Education	Below high school diploma	18 (51.50)	15 (42.90)	0.473**
	Above high school diploma	17 (48.50)	20 (57.10)	
Relationship with the patient	Spouse	17 (48.60)	18 (51.40)	0.694**
	Daughter/Son	14 (40)	15 (42.90)	
	Other	4 (11.50)	2 (5.80)	
Living with the patient or not	Yes	27 (77.10)	30 (85.70)	0.356**
	No	8 (22.90)	5 (14.30)	
Place of residence	City	34 (97.10)	35 (100)	1**
	Village	1 (2.90)	0	
Type of residence	Owner	25 (71.40)	26 (74.30)	0.788**
	Renting or other	10 (28.60)	9 (25.80)	

\*Independent *t*-test; \*\*Chi-square

**Table 3: Comparison of the mean scores of caregivers' burden at baseline, immediately after, and 1 month after the intervention in the intervention and control groups and estimation of the effect of the group and time using the repeated-measures ANCOVA**

Variable	Time	Groups		<i>p</i>	Interaction			
		Experimental Mean (SD)	Control Mean (SD)		<i>F</i> (df1, df2)	<i>p</i>	<i>F</i> (df1, df2)	<i>p</i>
Care burden	Preintervention	66.90 (11.50)	72 (6.60)	0.026	$F_{1,67}=1089$	<0.001	$F_{1,67}=0.276$	0.576
	Postintervention	23.90 (4.60)	73.60 (7.30)	<0.001				
	One-month follow-up	25.80 (5.90)	75.30 (7.50)	<0.001				

ANCOVA repeated measure

The present study also found that care burden increased gradually over the three measurement occasions (before, immediately after, and 1 month after the intervention) in the caregivers of the control group ( $p < 0.05$ ), which is in line with the findings of other studies.<sup>[18,19,24,31]</sup> This finding can be explained by noting that as the patient's disease progressed and as the caregivers in the control group received no social or educational support, they showed a more severe care burden over time, probably because they were exposed to different crises and especially due to the chronic nature of kidney failure. Contrary to the discussed studies, McMillan *et al.*<sup>[33]</sup> did not find significant results with their intervention and the control group also showed no increase in their care burden, which could be due to the research setting, as that study was conducted in the United States, where caregivers of patients with chronic illnesses have access to support and training. In addition, their control group received routine care and may have enjoyed better support and training compared to the control

group in the present study. Insignificant interaction effect of group and time has not supported a longtime effect of the intervention. Therefore, it is suggestible to engage in continuous education programs to get significant longtime effects. Future studies needed to design proper interventions to get desired longtime effects. The strength of this study was conducting family-based training program based on a strong theoretical framework. In addition, the intervention program, the assigned homework in each session, and letting the caregivers to give feedbacks were among other strength points of this study.

Limitation of our study was different places of data collection, which limits the generalizability of findings to the same settings. Based on these findings, the present family-based training program significantly reduced the mean score of care burden in the experimental group of caregivers of patients undergoing hemodialysis immediately and 1 month after the intervention.

## Conclusion

Finding of this study show that family-based training program can lead to reduction of burden in caregivers of patients undergoing hemodialysis. Therefore, planning and provision of such psychiatric services among caregivers of the chronic diseases as a vulnerable group are essential in mental health provision services. Moreover, considering the results of this study, we suggest encouraging nurses to establish educational programs such as family-based training program in order to maintain and improve caregivers' mental health.

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## Conflicts of interest

Nothing to declare.

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